

# SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

Vol. 11 No. 1

October 1999

www.state.ar.us/ascc

## Wizard of Invention Retires

After working more than thirty years for the state of Arkansas, Charles Crowson, Batesville, decided it was time for a change. He began his career in 1966 with Arkansas Rehabilitation Services. With a Bachelor's degree in Industrial Education, and a construction background as an Army Engineer, Charles felt this job was "made for me." Being able to help people help themselves and, at the same time, use his construction skills was a dream come true.

After 15 years, Charles was ready for a new challenge. He took advantage of an opportunity to be a Case Manager with the Arkansas Spinal Cord Commission (ASCC), a relatively new agency developed to provide case management services throughout the state to persons with spinal cord disabilities.

Again Charles' construction skills were an asset. During his 18 years as a Case Manager for ASCC, Charles became known as the "Wizard of Invention" because of his ability to repair, design and build equipment. He had the unique ability to size up a problem and find a solution. "I just enjoy trying to help people meet their needs," stated Charles. "I've always liked building and making things for people, especially something that will make life a littler easier and help increase independence." As a result, over the years many persons living in remote rural areas in northern Arkansas have benefitted from his ingenuity and creativity.

In 1994, **April Bates**, born with spina bifida, lived about 6-7 miles



from Batesville on a country road and was unable to maneuver her wheelchair outside. She could only watch as the other children played. A Barbie Jeep was purchased by a local church ladies group and Charles designed a floorboard modification and the steering wheel. With the help of **Blake**  Watkins, an engineer with Eastman Kodak in Batesville, a switch was installed on the steering wheel to allow April to operate the vehicle with hand controls.

Charles always carried a lot of spare parts in his truck and was ready any time to repair a wheel-chair, hospital bed or ramp. This allowed them to have their equipment usable in a short amount of time, instead of having to send off for repairs, which could have taken weeks.

Charles has reached another milestone in his life and it's time for another change. He has decided he would like to take time for some hunting and fishing and — oh yes, repairs at home! Charles retired August 1 and will be greatly missed by his clients and co-workers. Good luck, CC!

## **Wheelchair Tire Recycling Program**

ASCC is offering a new "Wheel-chair Tire Recycling Program" to clients who have wheelchairs with pneumatic tires size 24" x 1 3/8" and who can change a tire or have someone in the home who can. There are no financial eligibility criteria for this program.

The program is free and very simple. Your local ASCC Case Manager will give you a tire recycling bag containing tires, tubes and instructions. When you have a flat or need a replacement, you put the new tires and tubes on your wheelchair, put the old ones in the bag and contact your Case Manager for a replacement. Your Case

Manager will pick up the old bag and give you a new bag.

The only rules are that you must:

- a. Use pneumatic tires size 24" x 1 3/8" on your chair.
- b. Change the tires yourself or have someone in the home who can put the tires on for you.
- Return the old tires and tubes to your ASCC Case Manager to get a new set.

It is the Commission's hope that the Wheelchair Tire Recycling Program will prove to be a very useful service for our clients.

### SPINAL COURIER

Published quarterly by Arkansas Spinal Cord Commission

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### With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at 501-296-1788 / 800-459-1517 / TDD 501-296-1794, or send your donation to:

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### Donations this quarter from:

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### SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### **Common Thread**

Dear Editor:

A new parents group has been formed to serve parents and disabled individuals statewide who share common goals and beliefs and who want more and better services for themselves and their loved ones. The group, Common Thread, has been in the planning stage since July 1997. Our mission is to unite families to work together

to obtain choice and quality services for all individuals with disabilities. For more information about the organization, contact:

Common Thread 5 Cuenca Lane Hot Springs Village, AR 71909 E-Mail: skiplan@aol.com FAX: 501-922-1866

Debbie Ethridge, President Common Thread Bentonville, AR

### From the Director

It's been a good summer! I've been lucky to have the opportunity to get out and meet new people and to catch up with old friends and colleagues. It's always interesting to hear what interests and concerns people. By my best assessment, no one is very worried about Y2K—they are more worried about what they will do on New Year's Eve this year! The weather has worried all of us, my own concerns about keeping the lawn watered seem trivial in light of the hurricanes and droughts around the Country.

What people do seem to be concerned about is staying healthy! Maybe it's my age, but more and more, I seem to be touched by people facing health problems! This seems to be true from the young folks I meet at Spina Bifida Camp and Super Spokes to those I see at the CAPPS clinics, friends and family, and our own staff here at the Commission. The worst thing is, a lot of our health problems are preventable! Eating healthy foods, getting at least some exercise each day, and keeping a positive attitude can have a great effect on all of us. In addition, a few laughs and hugs have been shown to have a very positive effect on our health. When is the last time you went for a walk or a roll, just for the fun of it? Told a joke, just to hear someone laugh?

I think the best thing we can do as we approach the new millennium is to take care of ourselves! Healthy bodies and attitudes will give us a great advantage in Y2K! Think about it, or better yet, do something healthy!

Cheryl Vines

In Memory of Doug Powell
Mr. And Mrs. Charles Wadley
Staff of the Pine Bluff Arsenal
Wright, Lindsey, Jennings, LLP
Support Staff
Mitchell Bates

Mr. and Mrs. Walter May Virginia Dominguez Margaret Dominguez Ella May Kellerman Theresa Graves

# Nominees Sought for MS Grants

Clinicians are being asked to help select applicants for a new grant program targeting people with multiple sclerosis who are taking Betaseron (Interferon beta-1b).

Funded by Berlex Laboratories, manufacturer of Betaseron, the MS Champions of Courage program is designed to identify and support Betaseron patients who inspire and motivate other with the disease. Grants of \$7,000 each will be awarded to patients who have "demonstrated great courage and initiative in overcoming the disease, are involved in community service activities, and have an inspiring plan for how they would use [the] grant," according to the company.

Grant recipients will be selected by a six-member advisory board that includes neurologists and MS patients.

Company spokeswoman Liz Pendergast told Rehab Report that the awards will be ongoing: "When we receive a batch of good candidates, we will review and make an award. Those not awarded the first time around will go back in the hopper for the next review." She said Berlex aims to award three to five grants per year. For more information, call 800-788-1467 or visit the Berlex Web site at:

www.betaseron.com.

Reprinted with permission from Rehab Report, August 1999, page 10. Copies of this monthly magazine are available from Intertec Publishing, P.O. Box 8987, Malibu, CA 90265-8987. For information, call 800-543-4116.

# Spina Bifida Camp '99

Spina Bifida Camp, held at Camp Aldersgate July 4 - 9 this year, was a great success! All campers participated in various activities adapted so that everyone could participate to their fullest ability.





Activities at Camp ranged from arts and crafts, outdoor cooking, swimming, nature hiking, music and drama. **Kahlephia Johnson** (above - right) and **Amber Nicole Ivey** (above - left) learned how to fish.

Happy camper **Bojak** Cates (left) caught one!

campers
Pateal
Abazajian
(right - top)
and
Mallory
Stone
(right - below)
had fun
making
friends.

Carefree



Photos courtesy of Camp Aldersgate.

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# How Close Is a Cure for SCI?

# An Interview with Wise Young, MD

Wise Young, MD, PhD, director of the Neuroscience Center and the Spinal Cord Injury Project at Rutgers University, is an internationally renowned SCI research scientist. Among his accomplishments, Young participated in pioneering research that led to the development of high dose methylprednisolone as a treatment for acute SCI. This drug improves neurologic recovery by an average of about 20% when given to people within several hours after injury, and its use is now standard practice in SCI trauma care.

[Spinal Cord Injury Update] recently interviewed Young about the progress of SCI research today. His responses will be published in two installments; part 2 will appear in the next issue.

### Part 1

Q: Over the last year or two, there have been promising breakthroughs in nerve cell regeneration research. Which avenues of research do you think are most likely to lead to a cure for SCI?

A: Much research indicates that spinal axons can regrow but the spinal cord contains substances that prevent growth. Several therapeutic approaches have shown promise in animal studies.

1. Blocking growth inhibitors in the spinal cord. Martin Schwab and his colleagues at the University of Zurich discovered an antibody called IN-1, which appears to block the growth-inhibiting substances in the spinal cord. These inhibitors appear to be concentrated in myelin, a material that wraps around

spinal axons and improves conduction. Myelin is white and consequently areas of the spinal cord that contain myelin are called white matter (WM). Implantation of cells that produce IN-1 in rats promoted spinal cord regeneration. Much effort has gone into making a form of IN-1 that can be used in humans and IN-1 may well be one of the first therapies to go into clinical trial, perhaps in the next two years.

2. Diverting regenerating axons into gray matter. Heinreich Cheng, Lars Olson, and colleagues in Sweden showed that it is possible to get some regeneration to occur in rats by using peripheral nerve bridges to direct the growth of spinal axons into gray matter (GM), a part of the spinal cord that is more conducive to regeneration. Cheng and Olson's work lends credence to Schwab's finding that WM inhibits growth, demonstrates that axons can grow long distances in GM, and provides a potential surgical approach to reconnecting transected spinal cords.

3. Building cellular bridges. Several studies suggest that it is possible to use other cells and materials to bridge the gap. Doug Anderson and Paul Reier at the University of Florida at Gainesville transplanted fetal spinal cords to the injury site in humans, based on the notion that fetal cells might support some growth.

Two patients received fetal cell transplants last year in Florida and dozens have received such transplants in Sweden and Russia. Results from this procedure have been inconclusive so far. Mary Bunge and colleagues at the Miami Project have been using artificial bridges and Schwann cells. More recently, two groups (Geoffrey Raisman of the University of London and Mary Bunge) reported that a special kind of cell from the nose, called olfactory ensheathing glial cells, will support the regeneration of axons in the spinal cord.

### 4. Enhancing natural repair mechanisms.

Last year the Multicenter Animal Spinal Cord Injury Study, a consortium of SCI laboratories that are working together to develop and test therapies, discovered that

injured rat spinal cords show limited regeneration without any external therapy. This has led to intense studies of natural factors that may enhance regeneration.



Last month Michal Schwartz and her colleagues at the Weitzmann Institute reported that transplantation of activated

macrophages into transected rat spinal cord apparently promotes regeneration and some functional recovery in rats. In our laboratory at

Rutgers, we have found that injured spinal cords express a cellular

Continued on page 5 - See "Wise Young on Curing SCI"

# Wise Young on Curing SCI

Continued from page 4

adhesion molecule called L1, and administration of additional L1 to the spinal cord can enhance regeneration and functional recovery in the injured cord.

**Q:** Can you tell us about your current research?

A: We have devoted much of our effort to developing standardized tools for collaborative research in SCI, and we have validated outcome measures that many laboratories have adopted so that everybody knows what is meant when a rat is said to walk, when there is less tissue damage, or when there is regeneration. Using these tools, the field can now systematically develop and test therapies efficiently.

Most of our laboratory work is focused on four treatments: L1, M1. MP, and pregnenolone. L1 is a cellular adhesion molecule associated with increased growth and recovery in rats (see above). M1, an antibody discovered by Moses Rodriguez at the Mayo Clinic, is in the same family of antibodies as IN-1 (see above) and has been shown to promote remyelination in various animal models. MP is a corticosteroid that not only protects spinal cords against progressive tissue damage but may also promote regeneration. Pregnenolone, a steroid molecule produced by the central nervous system, makes spinal cords tolerant of prolonged oxygen deprivation, and others have reported that it improves repair and regeneration.

Two other projects in the laboratory are also quite exciting. First, we are systematically studying injured spinal cords to find out which molecules expressed after injury can signal axonal growth. If we can identify these signals, it



will be possible to apply them to the chronic cord to kickstart growth again.

Second, we have been transplanting fetal oliogodendroglial cells into the spinal cord. About a third of those with SCI have enough surviving axons but these axon have been demyelinated and can not effectively conduct signals. Last year, we showed that transplanted oliogodendroglial cells will remyelinate axons in rats with SCI.

The Spinal Cord Injury Project can be reached at Neuroscience Center, Rutgers University, 604 Allison, Rd., D413, Piscataway, NJ 08854-8082 (732-445-6573, 445-2061; SCIProj@biology.rutgers.edu).

**Next Issue:** In Part 2 of this interview, Wise Young proposes a timetable for a cure for SCI and cautions readers about unproved therapies.

This article was reprinted with permission from Spinal Cord Injury Update, Summer 1998, pages 1-2. Copies of this article are available from Spinal Cord Injury Update, University of Washington, Rehabilitation Medicine, Box 356490, Seattle, WA 98195-6490. For subscription information, call 206-685-3999.

### New ARS Commissioner

John C. Wyvill assumed the position of Commissioner of Arkansas Rehabilitation Services in early July. A graduate of Hendrix College and the University of Arkansas School of Law, John brings a wealth of experience and enthusiasm to his new position. A former aide to Governor Huckabee, John has been involved on the state and national level in disability issues. He has a strong commitment to customer service and to promoting employment opportunities for Arkansans with disabilities. Wyvill replaces Bobby Simpson, who recently assumed the position of Director of Rehabilitation Services in Oregon.

Please join the Commission members and staff of ASCC in welcoming John Wyvill as our new Rehab Commissioner.

# Flu Shot Time Again!

It's time for the flu injection again. The best time to get your annual flu injection is in October or November. You should either visit your doctor or the local Health Department clinic to obtain your flu injection.

At the same time, you should ask your doctor whether or not you need the pneumococcal vaccination. The Centers for Disease Control and Prevention recommends routine adminstration of the pneumococcal vaccine to persons over age 65, those with chronic respiratory disease and those who live in chronic-care facilities. This injection is, in most instances, needed only once in a lifetime, but might need to be repeated after ten years.

# Folate and Folic Acid — What's the Difference?

"Proof." That's a word you don't hear too often when people talk about vitamin supplements and disease . . . except when they're talking about folic acid.

It's been proved that folic acid can prevent neural tube defects. The defects occur when the neural tube—which becomes the spinal cord—fails to close 18 to 26 days after sperm meets egg. If the error occurs at the top of the tube, the child is born with anencephaly (no brain) and dies soon after birth. If the error occurs further down the spinal cord, the child is born with spina bifida (open spine). The damage to the spinal cord often keeps children in wheelchairs or on crutches for life.

Folic acid could prevent half of all neural tube defects if women were to start it shortly before they conceived. The catch is that half of all pregnancies are unplanned. So the U.S. Public Health Service recommends that "all women of child-bearing age in the United States

who are capable of becoming pregnant should consume 0.4 mg (400 micrograms, or mcg) of folic acid per day."

But the message has gotten blurred. The recommendation to get 400 mcg of folic acid—which occurs only in supplements and fortified foods—gets translated into 400 mcg of folate from foods.

There's a big difference between folate and folic acid! Folate refers to all forms of the B vitamin. Folic acid refers to the synthetic form found in pills and fortified foods. The synthetic form of folic acid is more easily absorbed by the body than the natural form which must be broken down by the body into a usable form.

In the clinical trials that proved that folic acid can prevent birth defects, women were eating their usual diets—which typically have about 200 mcg of folate—and were taking a folic acid pill. Everyone should eat a balanced healthy diet,

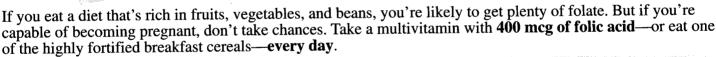
but there are no randomized clinical trials showing that 400 mcg of **folate from foods** alone prevents birth defects.

To boost folic acid intakes, the federal government started requiring manufacturers, as of January 1998, to add folic acid to any foods that contain enriched (white) flour-including breads, pasta and breakfast cereals. But don't assume that two slices of bread have all the folic acid you need. There are only about 15 to 25 mcg in a one-ounce slice. To get 400 mcg, you would have to eat a whole loaf! Instead, take a multivitamin. Fortified breakfast cereals are also a powerful source. A bowl of corn flakes has about 100 mcg. See Falling for Folate (below) for a list of common foods with their folate and folic acid levels.

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# Falling for Folate



Food (1/2 cup, unless specified)	Folate (mcg)	Food ( <u>1/2 cup, unless specified</u> )	Folate (mcg)
Orange (1)	40	Orange juice (I cup)	60
Multi-Grain Cheerios Plus cereal (1 cup)	400*	Product 19 cereal (1 cup)	400*
Most breakfast cereals (1 cup)	100*	Total cereal (3/4 cup)	400*
Pancakes (4 4-inch)	60*	Waffles, frozen (2)	40*
Wheat germ, toasted (1/4 cup)	100	Bagel (2 1/2 oz.)	50*
Bread, whole-wheat (1 slice)	15	Bread, white (1 slice)	15-25*
Pasta, cooked (1 cup)	100-120*	Rice, enriched (1 cup)	80*
Chickpeas or pinto beans	145	Black beans	130
Red kidney beans	115	Green peas or parsnips	45
Romaine lettuce, shredded (1 cup)	75	Collards	90
Spinach, raw (1 cup)	60	Spinach	130
Brussels sprouts or soybeans	45	Broccoli	40
Asparagus (5 spears)	110	Peanuts, dry roasted (1 oz.)	40

<sup>\*</sup>includes added folic acid.

Vegetables and beans are cooked unless otherwise noted.

Source: Manufacturers and USDA Nutrient Database for Standard Reference (www.nal.usda.gov/fnic/foodcomp).

### 1999-2000 Wheelchair Basketball Schedules

#### **AR Rollin' Razorbacks**

Nov. 13-14	Tulsa	
Dec. 4-5	Home	
Jan. 7-8	Nashville	
Jan. 15-16	Home	
Feb. 11-12	Birmingham	
Mar. 10-12	Sectionals	
Mar. 24-26	Regionals	
Apr. 7-8	Final Four in Chicago	
All home games are played at		

All home games are played at Sylvan Hills High School in Sherwood, AR. For more information, call **501-834-8513**.



### Ft. Smith Shooting Stars

Tulsa

Oct. 30

Dec. 4	Little Rock
Dec. 11	Memphis
Dec. 18	Fort Smith
Jan. 2	Oklahoma State University at Stillwater
Jan. 8	Muskogee, OK

For more information, call Doug Moore at 501-834-8513.

### Jr. Rollin' Razorbacks

#### Tentative Schedule:

Nov. 19-21	Mid-South Reg. in Hot Springs
Jan. 7-9	Dallas
Jan. 22-23	Chicago
Feb. 5-6	St. Louis
Feb. 19-20	8 1/2' Cham- pionships in Birmingham
Mar. 23-26	Junior Nationals in Berkeley

For more information, call Doug Garner at 501-525-4503.

# Attendant Care Training

Marsha Parker from the Arkansas Department of Health has announced that the Personal Care Department is conducting classes each month to teach people how to become attendants. Each class meets from 8:00 am to 4:00 pm for five consecutive days (see schedule below). If someone in your family, a neighbor or anyone you know would like to participate in this training, you may call 280-3376 for more information.

The classes are free and preregistration is not required. Classes are held on the third floor of the Health Department at 4815 W. Markham, Little Rock, AR.

A list of persons who have completed the course is maintained by the Health Department. For persons with spinal cord disabilities who need attendants, it will be necessary to get additional training to meet an individual's specific needs.

Schedule through 1999:

October 18-22 November 8-12 December 6-10

### ADSA Announce Fall '99 Schedule

The Arkansas Disabled Sportsmen Association (ADSA) is planning the following hunting activities in Arkansas this fall:

Oct. 16, 1999	Hunt in DesArc	
Oct. 24, 1999	Black powder hunt at Fra Lyons - participants to st DesArc Lodge	
Nov. 13, 1999	Hunt in DesArc	
Nov. 20, 1999	Hunt in DesArc	
Dec. 18, 1999	Hunt in DesArc	

Spring Turkey hunt in Heber Springs, with the date to be announced. Other sporting activities will include: Texas hog hunt, duck hunt, trout fishing trip at Heber Springs, guided fishing trip on Ouachita with John Hall and guided fishing trip on White River. For more information regarding these and other events call the Arkansas Disabled Sportsmen Association at 501-666-2523.

### New Resources in the McCluer Resource Center

The McCluer Education and Resource Center on Spinal Cord Injury has added a number of new items to its collection. If you are interested in checking out any of the resources, please call the Resource Center at 501-296-1792 or 800-459-1517. Some of the new additions include:

- Accessible Living (video), by ASCC Case Managers Martha Henderson and Daniel Cook, displays some of the adaptations used by persons with spinal cord injuries in their homes and vehicles.
- Go Where You Want to Go (video), by Independent Mobility Systems, is a short commercial video of van



adaptations offered by IMS, including "kneeling" and rearentry vans.

- Partner's Safe Approach to Patient Lifters (video), by Guardian, is a commercial video demonstrating the safe use of patient lifters with disabled persons. Shows a variety of transfers including from bed, from the floor, in the bathroom and to the car.
- Abriendose Camina a la Independencia: Mediante el Uso de Servicios de Asistentes Personales (audio), by Peg Nosek, is a Spanish language series of audiotapes on the utilization of personal assistants. Interviewing, hiring training and management are some of the topics covered.
- Sexuality and Spinal Cord Injury (book), by McDonald, Lloyd, Murphy and Russert. This book contains specific information about how the body works, relationships, parenting, birth control and myths about sex and spinal cord injury.

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